

Journey of Gathering Wisdoms: Sharing the Stories of Indigenous Women Through the CHIWOS Data



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BACKGROUND

Indigenous Researchers have been engaged in the **Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS)** from its conceptualization. Through CHIWOS, Indigenous Community Researchers (ICRs) collected data from **315** Indigenous Women Living with HIV over three waves (2013-2018) to better understand the role of Women-Centered HIV Care in the uptake of HIV services and care. This re-search journey continues ... the ICRs have been working with the CHIWOS data to honor the wisdom and stories behind the numbers and present the findings In a Good Way. As this re-search was grounded in the principles of Community-Based Research (CBR), community members have been equitably engaged throughout the research, and the team's processes are designed to contribute to positive changes for Indigenous communities.

METHODS

For this project, Indigenous Storytelling was at the heart of our work. Every step of our journey was grounded in Indigenous Ways of Knowing and Doing.

Water Ceremony

After the CHIWOS data collection was finalized, a Water Ceremony, led by Elders Mike and Geraldine Standup, was held to transfer the data to Indigenous Team Members. It was felt that the data be in the hands of the Indigenous Team Members to support self-determination of statistical analyses and interpretation.

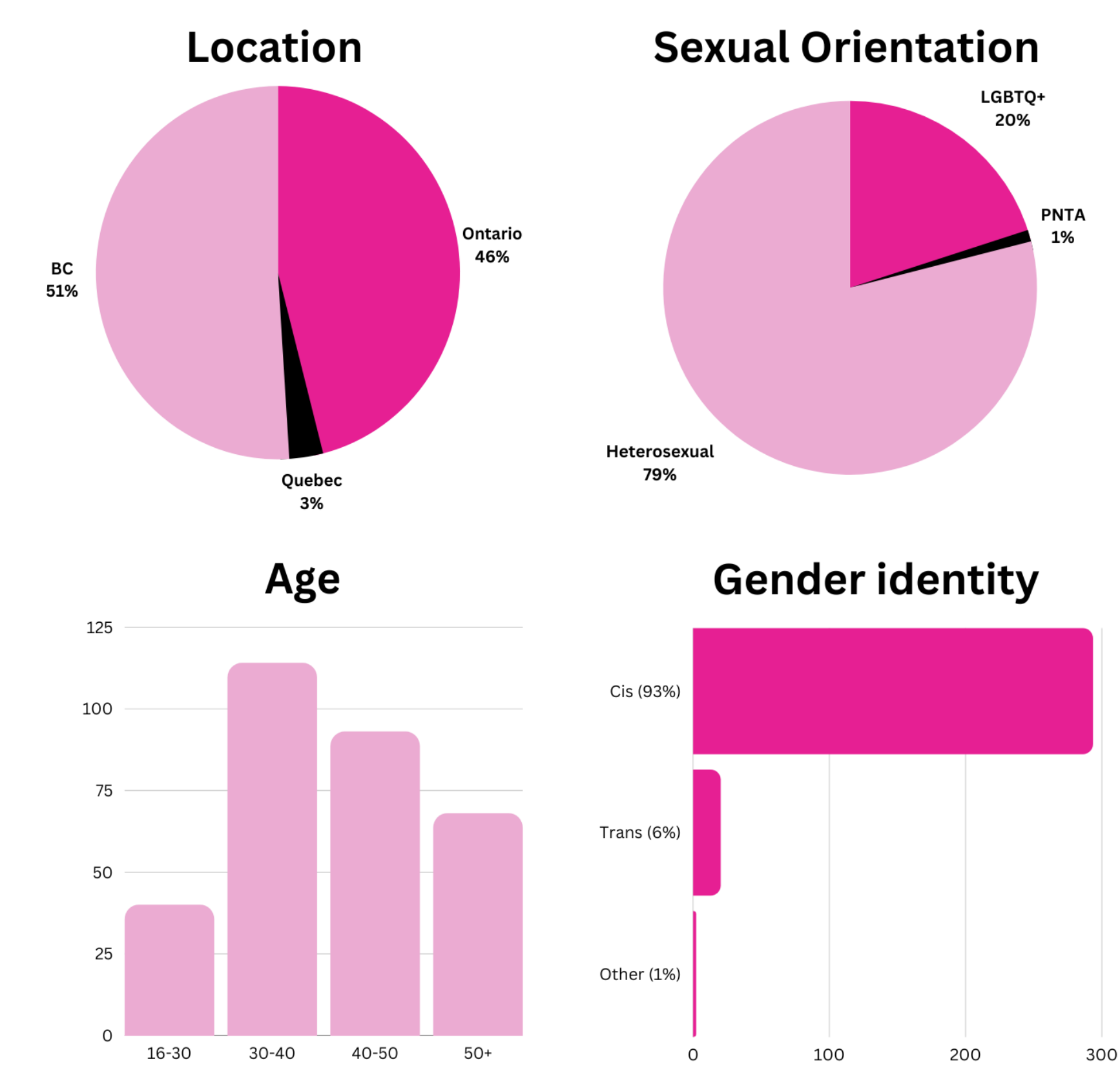
Analysis workshops and writing retreats

Upon completion of the statistical analyses, all members of the study team were invited to attend six 3-hour data discussions. After the workshops, a smaller team led manuscript preparation based on conclusions from the analysis workshops via fourteen collaborative meetings. Elder Valerie Nicholson opened and closed each meeting.



The Water Ceremony April 5, 2017, in unceded Kanien'kehá:ka territory (Montreal, QC), led by Elders Mike and Geraldine Standup. From left to right: M. Loutfy, C. Martin, R. Masching, C. Cardinal, J. Cotnam, V. Nicholson

THE WOMEN AT THE HEART OF THE NUMBERS



HIV Care and Treatment

The majority (**88%**) have accessed HIV medical care, **73%** were taking antiretrovirals (ART), and **63%** of women had a suppressed viral load.

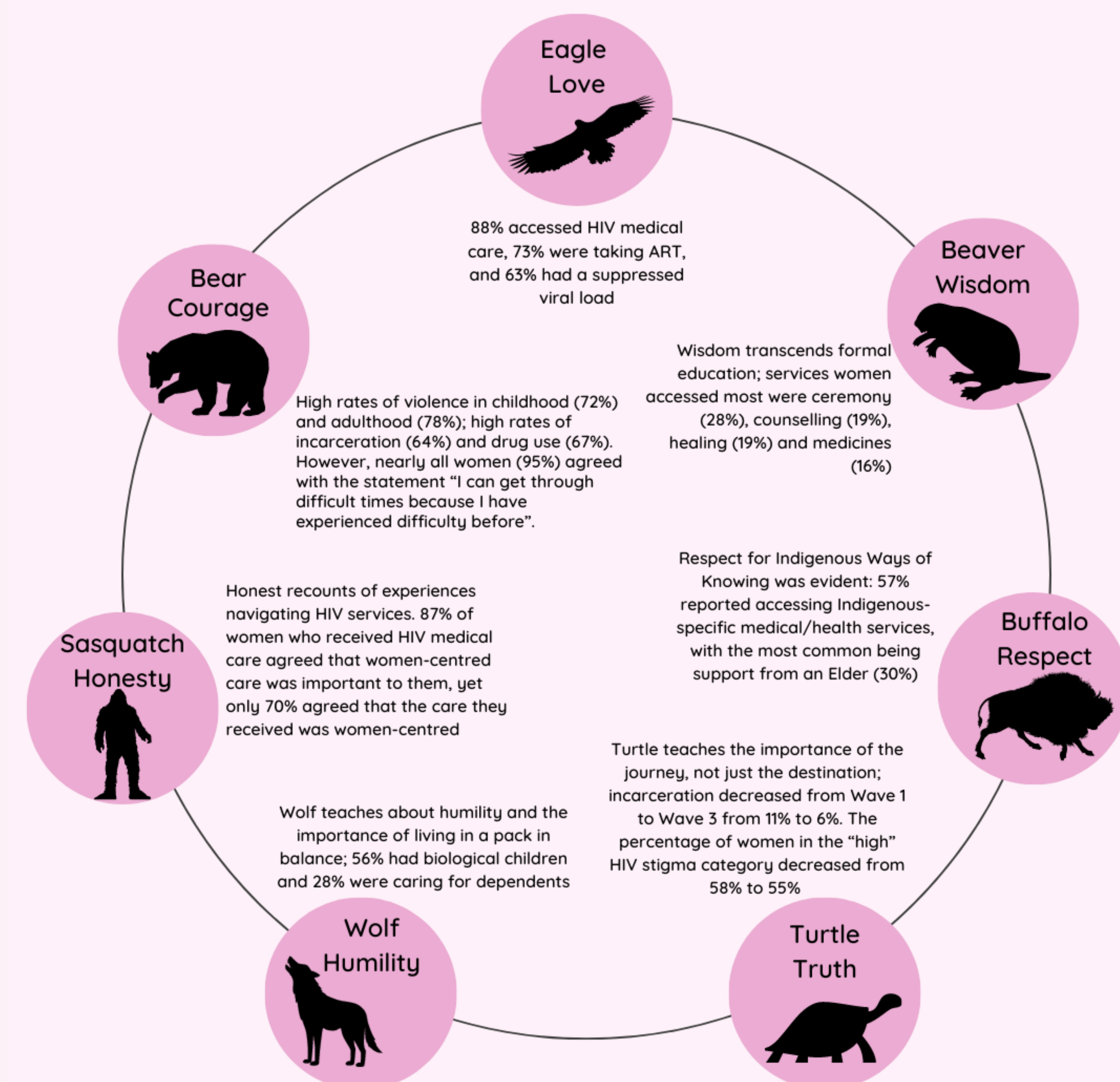
Social Support and Resilience

High resilience scores were reported, with a median RS-10 score of **90 [83, 100]** out of **100**. The women also had very high social support scores, with an average of **16** out of a maximum score of **20**. Personal (**38%**) and cultural (**30%**) belonging may have contributed to the women's courage to keep going. Also, **36%** said Indigenous spiritual beliefs or cultural practices were very or extremely important to them.

Family and housing

Almost **70%** of women had children (biological or adopted), while **28%** were caring for dependents. The majority reported having stable housing (**79%**).

STORIES EMERGING FROM THE NUMBERS



TEACHINGS AND LEARNINGS

This re-search journey of gathering the Indigenous Women's stories and wisdoms has been a long and enriching one. ICRs and allied researchers worked together to analyze and story the Indigenous Women's CHIWOS data. Using quotes from the Indigenous Women Living with HIV who contributed to CHIWOS, and linking them to the quantitative data, stories emerged that are now being shared with the broader community through the ICRs. When research data concerning Indigenous Women is analyzed and shared from their own perspective, we can truly honor the stories and wisdoms behind the numbers.

Epidemiological research is more than the figures and numbers. Behind each statistic and each number, there is a lived reality, a story that needs to be shared.

ACKNOWLEDGMENTS

Special thanks to Elders Valerie Nicholson, Mike and Geraldine Standup, and all the Indigenous Women who contributed to CHIWOS in various capacities, for sharing their wisdoms and stories. Without you, none of this would be possible. With the **28 Bear Paw** images below, we also honor the **28** Indigenous Women Living with HIV who have passed over to the Spirit World...your stories live on, and you are never forgotten.



Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada
Canadian HIV Women's Sexual and Reproductive Health Cohort Study

